Virtual Visioning Workshop

Advancing Social and Behavioral Science via Open Source Infrastructure for Research Using Smart Devices

Notes from Large Group Discussions Following Breakout Rooms

Data Collection Challenges

1. Sensing context on a device and the rate or timing of when information is uploaded; harnessing all the information that already is being collected on the device
2. Collecting a variety of types of data can be challenging–sensory data and survey data and GPS data and text and chat data and video data
3. Ensuring the information is easily accessible and analyzable to the researcher–they need to have a good user experience
4. Need to consider the software as well as the hardware–many devices (e.g., Garmins, Fitbits) have limits as to what can be collected and then downloaded
5. Not delivering a poor user experience to participants (e.g., slowing down their device) or influencing their behavior, unless that is a part of the study.

Ensuring Longevity, Relevance, and Inclusiveness of Platforms

1. As devices change, platforms can no longer be used
2. Need to be around long enough and accessible enough for many people to access–so they spread to many lab groups and institutions
3. Need to make sure underrepresented voices are heard at every stage of this process; need to convene the researchers and others that are not typically part of the process; maybe they can be co-owners
4. Building and elaborating on modules; start with a simple module for one study, but then be able to build on that for something more complex for the next study

5. Social and behavioral scientists must be part of the building process because they know what is needed on the user side–researchers and participants
6. But we should go outside the traditional communities, for example include undergraduates and others who participate in research to build what they will use; this has to be at the beginning
7. Whatever we design should be general enough that it can be used by multiple users–be careful about being too user-focused; more universal can be used with more people; core features will allow important work
8. Some standardized data collection is needed so that people can merge their data sets across labs; some standardization can be really simple (e.g., how demographic information is collected), but there could also be standardized modules for tasks like executive function or frequently used surveys

Other Important Issues

1. Recruitment of participants and keeping them in the study can be challenging; maybe gamification could be useful or providing information about them to keep them in the study–but must be careful not to get too select of a sample
2. With the way things are now, there is a big risk calculation about using smart devices because it is such a big time commitment, can ruin graduate student and junior faculty's career
3. For grants, it will need to be compelling that Rokwire is going to build things to specification in terms of HIPPA, security, etc.

Notes from Breakout Rooms

Session 1: Hurdles and needs

1. In what ways have you tried to use mobile apps or smart devices for your research? *(Suggested time: 10 minutes)*

- *Group 1:* Participants wearing Garmin wearables - measuring stress.
- *Group 3:* Apple Watch:
  - a. people's reaction to the environmental prompted by questions and instructions,
  - b. integration and association of data from different sources.
    - i. realtime heart rate, instructions: e.g. take a photo, how do you feel
    - ii. context info weather, street view, GPS points,
    - iii. sampling 20 min walk, every minute heart rate
    - iv. storage amazon cloud
- *Group 5:*
  - Federal nutrition education grant, working on building a tool or app to incorporate into state program. From public health world, not app development world, learning new language, barrier of

privacy concerns, reaching out to IT staff to be connected to people that can help tackle barriers
    - Oversampling vs undersampling from sensors, data is valuable at scale, barrier of keeping mobile app "on" and OS not closing app running in the background.
    - mHealth community could use/borrow tools from more established fields/industries, AWS is a great example,
    - Working with sensors that were not designed for our task, e.g., ECG, phone accelerometer and camera - the analytics become crucial - changing the paradigm to "there is no oversampling" as algorithms and methods improve, you can go back and reanalyze data. Hard to be confident you're doing the right thing.
- *Group 6:*
    - Eleanor - smartphones for daily diary studies. Uses social media to recruit participants. Text message reminders for saliva collection. YouTube videos to train on protocol
    - Shih-Han - custom app on iPhone and Apple Watch to access HealthKit data and obtain self-reports (via Apple Watch)and photos via iPhone
    - David - activity trackers, smartphones, smartwatches, connected water bottles, glasses & custom sensor harnesses
    - Homayoon - GPS

2. Known barriers/needs: What specific hurdles do you currently face in using mobile apps or smart devices for your research? They could be in any area, e.g., (app building, project management, and data processing, etc.) *(Suggested time: 10 minutes)*

- *Group 1:*
    - While working with Garmin, surveys are sent out once their heartrate went over a certain threshold. An issue they had was the company could not account for how many surveys each participant completed.
    - What questions to ask? What is asking for too much? Not having the background in app development makes it difficult to tell
- *Group 3:*
    - how to share the sensitive and identifiable data,
        - sharing model,
        - permission to MoU
- *Group 5:*
    - So many sensors with so much data, what should I do?
    - "Just do what I can afford" is one approach to which data types/sensors and what volume of data we could collect.
    - The extension typically has larger grant so funding isn't always the limitation. But a limitation is that there are so many different phones in the research population as well as software versions, etc.
    - "Five steps down the road and then two steps back" Develop the test, iterative approach- little bit of work then lots of feedback.
    - The extension has been around for 18-20 years so taking a

measured/intentional approach
    - What is the gap technology is filling? Target audience? How many touchpoints do we have for someone - where in the community is someone engaging with the program? How do these inform participant behavior?
- *Group 6:*
    - Eleanor - Parental consent (not a barrier but creates extra work working with children). Social media expands access beyond local area but not always a positive environment as these communities evolve.
    - Homayoon - GPS prohibited/limited in home country so moved to Maryland to pursue work improving urban design with this technology
    - David - institutional risk management and imagined threats that lead to overly restrictive policy environment and a terrible inertia that resists change at a large, complex institution

3. Unknown barriers/needs: In what areas could you use more training and information about how mobile apps and smart devices can be used for research? They could be in any area, e.g., (app building, project management, and data processing, etc.) *(Suggested time: 10 minutes)*

- *Group 1:*
    - Project management aspect - spending a lot of time talking to the company about what you want while competing with deadlines. Do you work with built-in project management within the company or do you hire someone on your team is the main point of contact for these activities? Want to ensure the team's interests are represented
- *Group 3:*
    - NIH data management plan, how efficiently match the requirements ?
    - How to measure the security of data.
- *Group 5:* [no recorded responses]
- *Group 6:* [no recorded responses]

Session 2: Visioning

1. How would you ideally like to use mobile apps or smart devices for your research? *(Suggested time: 10 minutes)*

- *Group 1:*
    - The wearables to be smaller
    - Survey design from the company: branching logic and sleek design
    - Mapping friendships and social connectivity via the mobile apps
- *Group 6:*
    - Context sensing; more information about specific moments while

respecting privacy
    - Making sure that information transfer is happening efficiently on participant devices; while respecting privacy needs; information transfer balanced with technological limitations; use power and not interfere with other functions
    - Standardized way of aggregating data; establish consensus regarding modular information for sharing
    - One stop shop app for multiple functions; recruit and engage participants, collect data and form communities with shared interests
    - Make it easy to integrate with other platforms like RedCap.
    - Create an app in which individuals are authentic; provides collection of raw data more synonymous with human behavior
    - Harnessing and aggregating the vast array of information that already exists on devices

2. How might we…
    i. Create an app for social-behavioral scientists that has the most useful features? *(Suggested time: 10 minutes)*

- *Group 1:*
    - Integrate data more easily to synchronize data from each source
    - Web service that allows researchers to create their own profiles and participants can give their permission for other researchers to use the data from one project to another
- *Group 6:*
    - Create a platform so individuals are able to pick and choose useful features or features of interest
    - Building sustainable apps, which are developed for longer periods of time; maintenance!
    - Build the foundational pieces that have a set of tools that social scientists pick and choose for their particular research project.
    - Connect with CTSI (clinical and translational science institutes) in the development of a common or shared platform that is kept up to date and maintained.
    - Implementing AI to evolve with platforms for longer sustainability; factors of the platform are updated in real time using AI

    ii. Make sure often under-represented voices in the technology development process are heard? *(Suggested time: 10 minutes)*

- *Group 1:*
    - The community help design the app - developing small pieces at a time so that they can bring it back to the community audience for feedback
- *Group 6:*
    - Seek out and engage specific communities at the design and

building phases; does the platform or technology meet their needs?
- Create opportunities for funded time to develop platforms and products, targeting underrepresented individuals and communities
- Being aware and discerning of the organic conversations already occurring regarding the need for spaces that are free from bias, the isms (e.g., racism, sexism) and the phobias (e.g., Islamophobia, homophobia)
- Make platform or app users co-owners of the product; results in marginalized communities embracing the products more wholeheartedly